



Dear Down Syndrome Community member in South Australia

It has been an exciting few months bringing together the on-ground team in South Australia, and what an incredible pair they are. I am delighted that Jennifer and Louise have joined our team and are working on ground in SA. As you will see below, they have been doing some incredible work to engage and support the community.

In WA we have continued to provide phone support to the SA Community and referrals where required to Jennifer and Louise. Our team is providing support for World Down Syndrome day with resources and help and we are delighted to see that you will be having an event at Government house.

I want to congratulate both Jennifer and Louise on the incredible start they have made in their roles and the work they are doing.

We are progressing with the commencement of a new association in SA. It was wonderful to see the support for the working group and from their feedback I am in

the process of drafting a constitution for an SA association. I have met with the Associations team from the SA Government to ensure we are across the requirements to register. We plan to have this draft to the working group in the coming fortnight.

In the background we are continuing to build the data base ensuring when you have a new Association you will have a member to commence with, commenced looking for future grant funding that may be available and supporting the SA team with resources, IT, new laptops and other support. If you know of any more families that have not yet registered on the database, please pass on this link: <https://forms.office.com/r/tBiBjDZQgY>


### **The Life Skills Lab – Empowering pathways to independent lives – Available to the SA community**

As you will have recently seen in an email to all families with a person with Down syndrome over 16years, Down Syndrome WA received funding to deliver a two-year project which includes delivery to regional WA, and we have expanded the project to include families in South Australia. This will be a series of workshops, presentations, and activities that we plan to make available online. If you haven't filled out the survey, we would love your input to build the best program possible.

Survey for Parents/Caregivers/Guardians - <https://forms.office.com/r/GXXLrD4sPA>  
Survey for Participants with Down Syndrome  
- <https://forms.office.com/r/A2ymehQ7KB>

### **Down Syndrome Regression Disorder**

Recently we held a parent support group catch up for those families who children/adults are/may be experiencing Down Syndrome Regression Disorder. We had people from all across Australia join. These meetings will be held quarterly. If you suspect that someone may be suffering with DSRD, the new resource created in WA is now available on the Down Syndrome Australia Resource hub and it can be found here: <https://www.downsyndrome.org.au/resources/> then click Down Syndrome Regression Disorder on the left hand menu.



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**Life Stage**

- ☐ Prenatal
- ☐ New Parent
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- ☐ School Years
- ☐ Teenagers
- ☐ Young Adults
- ☐ Adults
- ☐ Older Adults

**Category**


- ☐ Advocacy
- ☐ Community and Sport
- ☐ COVID-19
- ☐ Dementia
- ☒ Down Syndrome Regression Disorder



**Down Syndrome Regression Disorder Checklist**
Feb 2025

A DSRD symptom checklist to help guide families, GPs and specialists in assessment

DOWN SYNDROME REGRESSION DISORDER



**Down Syndrome Regression disorder – What it is and what can be done about it by Dr Cathy Franklin**
Aug 2024

Presentation slides from Dr Cathy Franklin's talk at the 2024 World Down Syndrome Congress.

DOWN SYNDROME REGRESSION DISORDER

If you have a family you think may have DSRD we would also encourage you to complete this survey which is collating data to support future research projects and through this, we can add you to the support group as well. <https://forms.office.com/r/L07pN7Z9ts>

Dr Cathy Franklin in Queensland is also running a survey and asking for your input.

*Can you help?*

**Do you support a person with  
Down Syndrome Regression Disorder (DSRD)  
or someone with Down syndrome who has had a  
recent decline in function?**

**Please answer  
our survey**



<http://bit.ly/4idqHNK>

 **Queensland Centre of Excellence**  
in Autism & Intellectual Disability Health

**Questions?**  
Contact Katie on 07 3163 1983 or  
[k.brooker1@uq.edu.au](mailto:k.brooker1@uq.edu.au)

Again, my thanks to Louise and Jennifer and to the SA community for your continued engagement and support as we work to develop a new association and to deliver services and support to you.

Please reach out at any time if we can provide further support.

Warmest regards

Cassandra

[ceo@downsyndromewa.org.au](mailto:ceo@downsyndromewa.org.au)

Mobile: 0432407527

## Employment Coordinator News

Wow - it's been a very big couple of weeks since commencing in the Employment Coordinators role for DSWA in South Australia! It has been a very productive time with lots of exciting things in the pipeline. The DSWA team have been such a fabulous support while I have been finding my feet in my new role.



We have had a sensational response to an Employment Survey sent to members recently. Thank you to all those who have responded - the information gathered will be pivotal in gathering important insights into employment readiness within our South Australian community. As part of our ongoing efforts to support individuals in the disability community, particularly those aged 18 and over. The survey will help us better tailor our programs and services to meet the unique needs of those interested in finding meaningful employment. It will provide valuable data to ensure that the support we offer is relevant and effective, whether it's through skill-building programs like the "Work Readiness Program" or connecting job seekers with potential employers. Your input will be incredibly valuable and if you haven't already done so we would encourage everyone ( aged 18 and over ) to complete the survey ( link below - and tell your friends ) to help guide our efforts in enhancing employment opportunities and resources for those in the South Australian Down syndrome community. We are looking forward to getting a plan together and beginning to offer some opportunities to our community members in the near future. <https://forms.office.com/r/LyWuUDY08V>

I have been working with the AFL Umpires Association and Down Syndrome Victoria to support the return of the Fiona McBurney Match Day Experience ( FMME ) to South Australia. Recommencing for the first time since 2019. FMME aims to provide a unique experience for individuals to undertake an official guest AFL trainer role for the AFL umpires on match day. The FMME program is named after the sister of retired AFL umpire Stephen McBurney, Fiona McBurney, who passed away in 2009, had Down syndrome and loved football, so naming the program after her was an ideal outcome for everyone involved. After completing an application recently four people were chosen to be the South Australian participants for the 2025 AFL season. On Wednesday 5th March the participants Michael, Jarrod, James, and Courtney took part in the SA launch of the program here in Adelaide.

Around 200 AFL and SANFL Umpires and family members watched on as they were introduced and received their match day uniform and certificate. They then enjoyed time working with a small group of umpires completing drills and learning about the umpire's hand signals etc - which was by far a favourite! On each participants match day they will be a guest trainer for the day, assisting umpires, be included in the coin toss, visit the changerooms prior to the game, have their name listed in the Footy Record under the Umpires and have photos captured by AFL media. Next year we hope to work together with the AFLUA and the AFL to increase the number of participants able to experience this fabulous opportunity. It was wonderful to have the chance at the Launch to share the story of the 'reciprocal joy' that this experience provides for all involved.



Following a survey sent late last year to our community members we have commenced a Working Group looking at redeveloping and reinitiating a community / family-based association here in South Australia. Thank you to the small group of proactive community members who have been working on this project.

Our initial meeting was very positive with a diverse group of people with a variety of skills who are passionate about collectively moving SA forward together! We hope to share our 'next steps' very soon. To support our working group, I have been communicating with Minister Nat Cook to share our intentions. I have also recently met with Felicity Crowther, CEO of South Australian Council of Intellectual Disability ( SACID ) to discuss potential possibilities and alignments. Information Service SA - Down Syndrome Australia staff will attend the annual SACID - Leading Through Inclusion Conference in June where the opportunity for people with micro-enterprise businesses is available to participate in - more information available on the SACID website.

I have recently worked with Sophie Campbell the Communications Manager for the Royal Flying Doctor Service ( RFDS ) Flying Doctor Podcast. On the nationwide podcast to be released soon Sophie and I discussed rural and regional health complexities particularly which additional health complexities associated with Down syndrome. We talked about some of the services and resources available to rural and regional families such as ours and in general if things have changed for people with Down syndrome over the years.

I have engaged with a Community Living Project ( CLP ) team in Adelaide who are running a Micro Enterprise event in April titled " Discover Micro Enterprise - Exploring Possibilities" - it is an information day of discussions and planning on Micro Enterprise as a career option for people with disability. This is a wonderful

opportunity for our community members to be involved in. See more information on our Info at SA Facebook page.

Excitedly we have been in conversations with Her Excellency the Honourable Frances Adamson AC, Governor of South Australia and her office to potentially organise a World Down Syndrome Day ( WDSO ) celebration picnic in the grounds of Government house in the near future. This would be a fabulous opportunity for our members of all ages to come together to celebrate WDSO - more details to come.

I am looking forward to touching base with those community members who have responded to our Employment Survey and working together to put some plans in place for the future.

Louise Taheny  
employmentsa@downsyndrome.org.au

## Family Support Officer News

Since beginning my role as Family Support Coordinator in January, time and time again I have been reminded of the important role our DS community plays in our lives and the lives of our loved ones with Down Syndrome.

From connecting new parents and families together, facilitating catch ups, answering requests for help, providing a listening ear or linking families with services, I have seen the power of our community and the impact it has on both our physical and mental wellbeing. There is nothing more validating than being surrounded by people with things in common and who simply 'get it'. I love that there's always an offer of support, advice or simply a hug available when it is needed most.

My first few months in the role of Family Support Coordinator have been, and will continue to be, rebuilding our South Australian community and connections.

I've started establishing new social media profiles and support groups while diving deep into understanding our community's needs, ways we can promote and maintain connections and gaining feedback from members on a whole range of topics.

One of our key priorities has been updating and maintaining our South Australian database. Louise and I had an outstanding response to ensuring our SA database is up-to-date and will continue to push this well into the future. Having an up-to-date database ensures all our South Australian Down Syndrome community is receiving current information, have an avenue for help and assistance and aid future planning. Additionally, this resource will play a crucial role in securing funding and grants for future initiatives in SA.

With World Down Syndrome Day fast approaching on March 21st, I'm excited to provide you with an extensive list of resources, activities, and handouts, developed in collaboration with Down Syndrome WA and Down Syndrome Australia, for educational, workplace, and care setting. If you'd like to receive a copy to share,

please email using the address below. We're excited to celebrate this special day and can't wait to see how you'll be celebrating!

As we continue to grow and strengthen our community, I'd love your support in spreading the word. Whether it's sharing information, welcoming new members, contributing advice, or simply reflecting on what our South Australian Down Syndrome community means to you, every bit of engagement counts. Your involvement will help us build a stronger, more connected network.

I'm always open to hearing your thoughts and ideas, and I'm here to assist wherever I can. Together, we can ensure our community continues to thrive.

Jennifer McCullough

famsupportsa@downsyndrome.org.au

Family Support Coordinator – Available Thursdays and Fridays.

Monday – Friday the SA Information Service phone and email is answered by the DSA WA team and referrals sent to the on ground team as required.

## Thanks for reading!



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